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ABSTRACT

This guide, based on a qualitative research study which identified primary stressors in families of children with traumatic brain injury (TBI), presents: (1) a summary of the needs of families affected by TBI; and (2) a proposed theoretical intervention model to meet those needs. The first section attempts to describe the present system of services focusing primarily upon its limitations through a personal account of the frustrations one family experienced in trying to get temporary care for a TBI son as well as through selected quotes from parents who attended a disabilities research conference in October 1989. Annotations to the parental comments are provided for clarification and a section labelled "Interpretation" follow each group of parental commentary. Interpretations of parent needs underline their concern for their other children, their desire to experience as normal a life as possible, their desire to be integrated into community life, and their need for competent and respectful help. Section II presents possible new directions for people needing help in the areas of expanding supports (to include cognitive and behavioral therapies and such stress reducers as arranging transportation). New directions discussed include Medicaid reforms to support parents trying to care for their children at home, expanding the scope of worker expertise and practice, a family centered emphasis in all services, improved teaching/training services, and seeing parents as case managers. Specific suggestions for agencies providing direct services are also offered. An appendix lists the unmet family needs identified by the survey. Includes 6 references. (DB)

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In Home Family Supports:

What Families of Youngsters with Traumatic Brain Injury Really Need

by Betty Pieper, B.S. Ed., R.N.,C.

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About The New York State Head Injury Association (NYSHIA): The Association began as a family organization. It was founded by parents who sought better services for their children and for their families. More recently, people with traumatic brain injury have assumed an active role in shaping the priorities of the Association and this has supplied the grassroots of the organization with new vigor and new growth.

From its inception the Association has been blessed with the support and involvement of professionals in every related field and in government as well. The Association has also matured with the participation of these people in rank and file membership activities and on the NYSHIA Board of Directors and through the Association's Professional Council and Provider Council.

In 1988, the NYSHIA was awarded a research grant from the National Institute of Disability Research and Rehabilitation (NIDRR) to identify primary stressors in families of children with TBI and to recommend the kinds of resources and models which should best meet their needs. The project, appropriately named Model Family-Professional Partnerships in Interventions for Children with Traumatic Brain Injury, was designed with both qualitative and quantitative research components. An Association founder and former Executive Director, Pamela Burns, is a parent/professional; she served as the Principal Investigator during the first year of the grant. The principle of parent-professional partnership is embodied in the current staffing of the project through the principal investigator, Dr. Susan Cox, who is a licensed psychologist, and the director of the grant, Betty Pieper, who is a parent and a professional registered nurse with certification in education and community health.

About this Report: Although parents and primary caregivers were not asked specifically about "in home family supports," the needs, hopes and fears as well as the expectations and investments which parents are making every day are readily apparent from our research and are corroborated by the findings of others. We hope that this summary - and the theoretical model put forth - will stimulate the kinds of discussion, interventions, supports and services families need and deserve. The author wishes to thank Dr. Susan Cox for her assistance and support and Brendon Mooney, a parent-professional and Chairperson of the grant's Advisory Committee, for his thorough review and helpful suggestions. Appreciation is also extended to Marilyn Lash, Alexandra Douglas, Clarence Sundram, and Douglas Biklen who offered general encouragement, comments and support.

Susan Cox, Ph.D.
Betty Pieper, R.N.,C.

In Home Family Supports: What Families of Youngsters with Traumatic Brain Injury Really Need

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In Home Family Supports: What Families of Youngsters with Traumatic Brain Injury Really Need

by Betty Pieper, B.S. Ed., R.N.,C.

The facilitator's first question: "What in your life is most stressful?"

The first parent's first answer: "A constant fear of who is going to care for this child when I no longer can. That's constant. It's with me every waking minute of every day. I just don't know who is going to take care of her when I can't."

To the lay person this exchange may seem to relate more to the need for estate planning, building a sufficient trust fund, or selecting a guardian than for in-home supports. Nothing could be further from the truth. Parents of children with significant disabilities and special needs often put off appointing guardians for the very reason that they do not feel confident that anyone they know could or would adequately oversee their child's care when they become unable to do so. Often parents cannot believe or trust that anyone could or would care for their child adequately after their deaths because they have been unable to find dependable, high quality care during their lives.

Many parents simply cannot find the kind of day-to-day care they need and desire. If they cannot find dependable caregivers for even short periods of time, they reason, how can they trust that this care will be available miraculously when they become too old or disabled--or dead? It is not just a matter of money, either. To quote one parent who took part in the NYSHIA parent research conference: "Even if you were a millionaire, you couldn't pay for the services you want."

Do the fears and anxieties expressed by parents represent an unrealistic reluctance or even fear of having others provide care? Or is it more a comment on the availability, kind, quality and cost of care? Obviously many parents find and accept good care; they begin to pursue or resume their own lives with appreciation for that care. However, as a class, families with children who have significant disabilities or special behavioral and health needs seem to have problems, whether large or small, in obtaining appropriate support. Other groups (e.g. caregivers of people who are frail from age, who have Alzheimer's disease, or who have AIDS) commonly express the need for flexible, easily accessed care of high quality, thus closely paralleling the concerns of parents of children who have suffered traumatic brain injury.

Section I: What's Wrong As the People Tell It

Overview

Some parents report that they have not had a caregiving "break" for their own purposes ("respite") in 16 years because no one can lift and position their son, or give him medication, or stay past 10 o'clock at night, or come on Saturday, or feed him through a gastric tube, or ... If someone can be found who can feed the child through a gastric tube or tend the ventilator and give medication, that professional may not lift and probably will not start supper or stay past 10 o'clock at night, come on a Saturday, or --. Or, the competent and motivated caregiver doesn't have reliable transportation. Families struggling to find care at home become familiar with the "endless *OR*" which instead of signifying additional choice for the family, inevitably signifies a limit on what can be done.

Case managers feel frustrated, too, when they survey every home health agency in 3 counties and cannot find someone who will be able to come once a week and take the child who is in a wheelchair from the school bus into the house, give him a drink and lay him on the bed until his mother returns from her once a week late class. It can't be done. The available aide cannot lift 50 pounds, or no aide can be found who will travel 2 miles past the village limits into "the country," or the agency does not permit any service for less than 2 hours duration. When the family says they will pay for the extra time even though it is not needed, it still can't be done because no agency aide wants to take on a small, once-a-week job, or ... endlessly ... it may seem.

Is it easier to find in-home care on a daily, routine basis, say, from 6:45 AM to 5:30 PM which would allow a parent to work? Not necessarily. Most of the same problems exist and some additional barriers as well. Namely, who will pay? Few parents have jobs which would allow them to break even, let alone make money for the family's use after paying a home health agency for child care. The fee per hour may be more than the parent earns even before taxes, travel and other job related expense. Many funding sources reimburse only for respite or medical emergencies but not for "routine care" related to holding a job. Further, the kind of schedule which would enable a family caregiver to hold a job is the kind of a schedule which may call for two shifts of in-home aides. Finding two people, with appropriate back-up, may be impossible.

It is usually the mother who has to give up her job. Sometimes it is because no one can be found to take a child to different therapies two or three times a week, or to various doctors and other necessary appointments. Or, a mother has to give up her job in order to take care of the child when he is ill because no home health worker is available when notice is given only the night before let alone the morning that illness is discovered in a child. Many, if not most, work situations are not flexible enough to feature family leave or to adapt to intermittent family crises or even routine commitments which are well above average. Because of this lack of "on-demand" child care, parents tell of not even being able to attend a loved one's funeral -- even, at times, the funeral of their own parents.

A major finding in a recent report from the Developmental Disabilities Planning Council of New York State (January 1990)[1] relates to both the unavailability and inflexibility of supports. "Lack of appropriate or available family support services, such as respite, crisis intervention, and financial assistance inhibit the ability of individuals and their families to maintain stability and independence. Families need flexible services, available when they need them, not necessarily when someone else decides that they can be offered to them."

In reality, the whole family, not one person, suffers the effects of injury, but current public policy results in the practice of patient-centered care at the expense of family-centered care. For example, even when the services to be delivered are non-specific (meal preparation, childcare and laundry), it is necessary to identify "a patient" or "a client" for reimbursement purposes. The agency home health aide is usually instructed to take care of only one person, thus requiring a second person to be hired for the same time if there are other dependent children in the family.

The problems related to family supports in the home are not unique to New York. A recent report (Minnesota State Planning Agency, January 1991)[2] notes: "The county had difficulty locating a provider who would travel to Becky's home. Once a provider was found, the provider refused to care for both children. A child care provider would now be needed in addition to the respite provider. The cost to the county for the respite provider was around $10.00 per hour. Becky has a neighbor who would provide care for both her children for $4.00 per hour, but the county would not authorize payment."

A report cannot adequately communicate the true dilemma of families caused by the need for patient or client care rather than family support. Parents are obliged, for example, to prepare food ahead of time for the non-client children and even to separate laundry by person so that the aide can deal only with "the client" or his personal effects and needs. In reality, many agencies and many workers stretch this criterion, but it is nonetheless an important barrier to efficient and humane service.

At best the practice of segregating care does not acknowledge the real needs of a family, and, at worst, it sets destructive patterns and attitudes in motion both within the family and with caregivers. The Minnesota report notes that "Formal supports and specialized services are often more costly than those garnered in the neighborhood or through family and friends. Not only that, formal services may be unable to efficiently meet the family's needs." These kinds of problems are among the prime reasons that families and other advocates are calling for direct family subsidies so that families may chose their own caregivers and pay them directly without the intervention of agencies.

Organization of This Paper: Section I of this paper seeks to take a snapshot of the present system, focusing primarily upon the limitations through a personal account ("One Woman's Story") and selected comments from the New York State Head Injury Association's 1989 Parent Consensus Conference. Author interpretations are addressed to policymakers and program designers. Section II sets forth a model which seeks to combine the best of specialized services which are based specifically on an individual's need with the choice and control families want. The model makes extensive use of the informal supports of a neighborhood and community and may or may not be agency coordinated.

One Woman's Story

When It's Done, but Badly: "Perhaps the only thing worse than not having service is having bad service or being promised service and then not having it forthcoming. It seemed that for years Jeff was always 'home' and so was I. Even when I planned something for myself or for his sister, Julie, an illness always seemed to intervene, or, the activity was scheduled to run past 3:15 PM when I had to make the mad dash home for his school bus. I vowed that this time would be different. Nothing would interfere. I was to accompany Julie's class on a full day, school sponsored conference out-of-town. I would be gone from before 8 AM until nearly 5 PM. And, if I could find care, I would go, sickness or not.

Unfortunately, Jeff ended up with bronchial pneumonia, an illness which was to keep him out of school for all but 11 days from September to January. I had registered my request months ahead for an aide who could care for Jeff all day. The agency assured me that all was well. The aide would be a man who could lift Jeff. He didn't mind a one-day-only job because he had sufficient time to arrange other work around it, and he was "familiar with wheelchairs and sick people."

We made everything easy. Jeff would sit in his chair until 10:30 AM, then the aide would: 1.) give him a drink, 2.) transfer him to the bed, and 3.) remove his back brace. My husband would come home at noon and do the postural drainage, make Jeff a special soft lunch, give him medication, take off the external catheter and leg bag, catheterize him, put an external catheter and leg bag urine collector back on, put his back brace on, get him into his wheelchair and position him properly. At 2:30 PM, the aide would do his 3 tasks again: give Jeff a drink, transfer him to the bed and remove his back brace. When the aide reached for a cigarette immediately after he shook my hand that morning, I made one additional request: please, don't smoke inside because Jeff was having great difficulty breathing.

When we came home that afternoon, I opened the door and found a house blue with smoke. I approached Jeff who was not on the bed but in the bed in pajamas and covered up. After my initial scare, I knew that this was an "extra," something a hospital-trained aide who wore a white uniform into a private home, would think befitting Jeff's 'patient' status. Then I hit the squidgy carpet underfoot. "What is this?" I asked. The inquiry served double duty because I also wondered why Jeff had a large, hospital sized bag attached to his external catheter instead of the small leg bag which had been hidden under his street clothes when I left. "Oh, I put that on so that I wouldn't have to empty it as much," he explained. "But why is the rug soaked, what is it?" I pursued. "Oh, I forgot to close the spout on the bag," came the reply.

When It's Promised and Not Done: The kind of experience noted above pales by comparison to some of the times aides failed to show up at all. For example, on another occasion, I was scheduled weeks ahead for a hysterectomy. Partly because of my anxiety about whether or not I could find care for Jeff and partly because of my personal philosophy, I had exhausted all reasonable alternatives to this surgery. Because, however, the procedure was not urgent, I was able to plan ahead. I shudder to think what worse could befall a child when there is a true medical emergency with no such opportunity for planning.

Our daughter had an after school, out-of-town basketball game scheduled for the day of my surgery. By finding someone to take care of Jeff when he came home from school at 3:30 PM, Julie would be able to play in her game and my husband would be able to visit me for an hour or so after his work day. He would then go home to relieve the aide and make dinner. The home health aide came the day before my admission in order to meet Jeff and to have me demonstrate what she should do (give him a drink and lay him on the bed.) That way she would know where the house was, how long it would take her to get there, and, in general, feel comfortable with the situation. She was also to assist me for several days after the surgery when I was not supposed to lift Jeff.

The weather turned terrible the day of my surgery, bad enough to force cancellation of Julie's out-of-town basketball game. Being the reliable daughter that she is, she came directly home on the first school bus available. Had she not done that, or had her bus been detained, her brother most surely would have died for she found him sitting in his wheelchair outside of the house on an open porch beaten by the foulest winds. No one had shown up from the home health agency, no one at all. And, for the first time ever, Jeff's bus driver simply left Jeff outside even though I did not come out to meet them as usual. Thus, the son we saw through 30 major surgeries in 3 cities far from home at incredible expense to us all in human and monetary terms nearly died on a hillside as if this had been the days of Sparta when people like Jeff were simply left out of sight to die of the elements. I can only tell this story from my viewpoint; to this day it is too painful for me to think about what Jeff must have experienced as he sat in the storm that day.

Sweating the Small Things: In our experience we have been enormously frustrated by 'the small things.' Things which by comparison to the large concerns are almost laughable, except that they are not. When you are already leading a harried life, the muddy floor left from the aide tracking mud in, is enough to make you want to sit down and cry. The food spilled--or sloppily wiped up--becomes a personal affront. The dozens of black scuff marks on the tile floor which literally bring you to your knees for hours of scrubbing and waxing are probably quietly taken in stride because at least this aide has a working car and has shown up twice on time.

The aide who let's you know that you buy your groceries in the wrong store and pay 2 cents more for a can of peas than she does has not only given you her 2 cents worth, she has violated your sense of self and your choices in your own home. The transportation problems of 'your' workers become your own. Their personal, marital and family troubles are often extreme and often shared. They can become burdensome because you can identify, yet the last thing you may need someone else's problems.

Stolen binoculars, records, or tapes are a loss partly because you have very little money for pleasures. They are a larger loss, too, because each time you lose a little more faith in humankind and in the people who are supposed to be helping you -- and you are little more afraid to become old, disabled or to die.

Rays of Light: Now and again, however, there are rays of light. One time, for example, a young man came to take care of Jeff for 5 days -- the longest period we had ever been away from Jeff. Although this worker had no particular 'clinical' training, he was willing to take care of Jeff. He felt overwhelmed when I demonstrated the intermittent catheterization technique for Jeff, however, and this was the prescribed ongoing care. We decided we could scrap the procedure for our vacation in favor of an indwelling catheter which would provide Jeff with essentially the same benefits if Alan were willing. He was and we left.
We had the time of our lives and so did Jeff. Alan cooked for him, joked with him, talked to him, and enjoyed him. Jeff seemed more mature and 'proud' (there is no other way to say it) when we came home.

He really cared about Alan and would ask me about his friend for years afterward. Happily this person is still involved in human service work. Although his present position does not involve direct care for people like Jeff, he often interacts with people with disabilities at a caregiving and care exchanging level.

Conference Participants Speak

The following comments are excerpted from the parent conference held as part of an NYSHIA/NIDRR research project in October, 1989. In that meeting, parents were asked to describe their stressors and later to describe possible interventions. Efforts were made to balance the parental sample by geography within the state, by rural and urban residency, by economic status, by marital status, by severity of injury, etc. Nevertheless, these comments (in bold italics) should not be taken to be representative of all parents or even to be specific to the "home health care" field. Rather they are selected to give the reader insight into parental feelings, experience and need. The comments seem congruent with the findings from over 200 respondents in our quantitative research component, the Family Questionnaire survey approach. (See Appendix for Unmet Needs.) Indeed, we expect that these comments add accuracy and example to the survey findings. It is hoped that this insight will prove valuable for those who are seeking to design and fund flexible in-home supports. Annotations to the parental comments are provided for clarification and transition under sections titled **"Experience."** A section labelled **"Interpretation"** follows each group of parental commentary. Both annotations and interpretations are the author's unless otherwise indicated.

What Parents Need and Want For Their Children - *The Ones Who Have Sustained a Traumatic Brain Injury*

Experience: In describing stressors (a goal of the conference), a dynamic balance exists between parents talking about their own needs and the needs of their children. At one point, a father felt that the group was getting afield from the real crux and states his belief that everything emanates from the injured child. In a separate but related exchange, a mother stated clearly that for her the welfare of the child is primary.

- ***"What about our children that are suffering this? We are forgetting them. They are the main people here. -- I don't know about anybody in the room, but I have dedicated the last 5 years of my life to my son. -- I feel he comes first, before my personal life and my personal well being, because that's the person we are fighting for."***

- ***"Of course my first concern is my daughter's welfare, the care of my daughter. That's number one."***

One mother expressed her personal hurt and frustration with the way workers seem to perceive and relate to her child.

- ***"They feel there is nothing to work with. I feel they are wrong. They spend 5 minutes with her."***

A father expressed his need to have good communications between home and school on a day to day basis; the comment is included because we have heard similar comments regarding in-home workers. While the workers in the home may write notes to and for each other from shift to shift or from day to day, the comments from parents may not be responded to and parents often lack feedback as well. The implication

is that not only may the child's care suffer from a lack of important information but that the parental expertise is devalued and their authority undermined.

- ***"I want to know what goes on everyday. -- If my wife writes a note and later you find the note and they haven't even looked at it--."***

The same father, perhaps perceiving that those in authority may communicate better with each other or believe or understand professionals with licensure more than they do parents, voiced frustration at the lack of communication between home, school and rehabilitation settings.

- ***"--They should contact the hospital therapist to find out what you are doing, what do you want us to be doing with your daughter. They are not coordinated."***

Still focusing on the child, parents commented on the social isolation and ultimately the painful alienation they and their children bear. One mother longs for some active assistance in creating interactions with peers for her son, and another goes beyond "social" to express the terrible loss of "friends" both for her child and for her and her husband -- a frequent and poignant theme for parents of young people who have suffered a head injury.

- ***"I would like to have some social life for my son because he needs his age group. If he didn't have his brother he would be just with me, and it's really boring."***

- ***"She has lost every friend in the world -- as we have."***

Interpretation: Through their comments, parents seem to say "I have to feel OK about my child's care and treatment before I can feel OK myself." This does not mean that families require miracle cures, but that they want to know that their children are getting quality care which is specific to their needs at any given time.

They want caregivers to value their children and to believe in growth. They do not want people around their children who have "given up" or act as if they are performing maintenance on a car. They would like to see professional competencies in the worker. While this doesn't necessarily mean that the worker needs to be a professional clinician or educator, it does mean that the worker must have some knowledge of human growth and development. It means that the worker should understand the characteristic behaviors associated with damage from TBI in the individual child so that they anticipate and accept those behaviors and use appropriate interventions. Parents want to know that the child may at least maintain and hopefully increase his skills, language, and learning because of the interactions between the child and the worker.

They want to know that their child will be accepted by others socially. They want the worker to act to maintain and improve the child's appearance and hygiene as well as his health and comfort. They want workers to LISTEN to them as the experts on the care of their children and to communicate with them about what has happened in their absence.

Parents would like to know that this person who has access to their home and to their child is a friend and an advocate. They would like to have the same caregiver instead of having people come and go. The lack of continuity in caregivers is particularly hurtful to a child and family who have already experienced great losses. A child may be confused, embarrassed or even frightened by various different people showing up to care for him. Eventually some children seem to think of themselves as a piece of equipment on an assembly line touched by numerous human hands without human-to-human contact. When warm relationships do develop between workers and families, and are then lost, it may be difficult, but most parents prefer this -- especially when the worker explains and follows-up with an occasional call or card.

Parents would apparently like to have caregivers who are trained in using valued, community services and in facilitating social acceptance and integration for the child in the neighborhood, in the school and in the community. This would be a new role for the worker and one which may indeed run counter to the hospital based training which many home health workers have at present or even the clinical type training featured in the pre-service education from home health agencies. The new role is discussed at greater length later in Section II: *New Kinds of Supports and New Kinds of Services, The Goal and the Role.*

What Parents Need and Want For Their Children - (The Ones Who Have Sustained a Traumatic Brain Injury) *And Their "Other Children" Who Have Also Been Hurt*

Experience: Parents talked at length about their "other children." Those perceptions are reported in another document, "Sisters and Brothers, Brothers and Sisters of Children Who Are Traumatically Brain Injured." One comment seemed to capture their concern.

- ***"Knowing that our family at home is taken care of. (Pause.) Are they going to school? Are their clothes clean?"***

Interpretation: On the surface, this quotation seems to express only concern for the physical state of the "other children" in the family. But it captures the immediacy of parental concern for the other children and the scope of their caring. In our interviews and meetings, parents gave extensive and eloquent testimony to their awareness of their "other" children's feelings of being displaced and of their expressions of guilt, anger, and fear.

Parents do not want these precious children to become displaced persons. And, parents feel cheated themselves when they cannot spend time with all of their offspring. They feel empathy for the brothers and sisters of the child who have gone into the hospital and been frightened by the injured child's appearance or have been afraid to fall asleep for fear they, too, will be in a coma. Parents worry whether their other children understand and if they will forgive them for their focus upon the injured child. They see the activities of all of their children constrained by the care and financial demands of the injured child and they feel sorrow.

These parents discussed at length ways in which they thought their other children could be helped. They recommended special assistance such as counseling, special sibling support groups, and the opportunity of appropriate child care so that they could spend time with each child individually as typical parents do as well as the inclusion of all of their children in activities where that is usual.

The message is clear. If in-home support workers or agencies want to serve families, they must treat all of the children in the family with respect and sensitivity and must design their services in such a way as to include everyone. Probably most in-home workers prefer this as well, but in the past they have been constrained by policies which are driven by funding restraints. Thus, a significant portion of the reforms we recommend needs to be addressed at state and federal levels through legislation, regulation, policy and funding mechanisms.

What, in General, Stresses Parents and What Do They Want for Themselves?

Experience: Parents seemed to feel that they needed some kind of personal support which may go beyond respite and which was not as simple or narrow as "counseling." This view is reflected in the following kinds of remarks:

- ***"How do you find someone who responds to your emotional state?"***

- ***"How do you deal with personal burnout? You have reached the maximum you can reach. How does somebody pick you up and put you back on your feet?"***

The concern for one's own strength, renewal or ability to carry on, is connected by one mother to the chronic concern of what will happen if and when the parent is not there.

- ***"What is going to be left of me? That's a very selfish thought, but it is as unselfish as it is selfish. Who is going to take care when I can't?"***

One mother noted that one can become a hostage to time and voiced the reality that *time* is necessary to work on the husband wife relationship. She also acknowledges that work is necessary, perhaps implying that special skills or assistance may be helpful in that process as well.

- ***"The extreme needs. It's just that we are always so busy. There is no time for a relationship between us, and we are the foundation for our family. -- The stress that comes because you don't have time to work on your own relationship, which is fundamental ."***

Interpretation: Perhaps what parents want most is to experience a life as close to the life they would have experienced if their child had not been injured. They want to have an opportunity to hold jobs, develop careers, build financial security, have time for personal growth and development -- and have time to do nothing.

Instead, many parents report being required by circumstance to give up paid employment, having to stay in unrewarding or difficult jobs because their insurance will not cover the child if they change, living in fear of personal bankruptcy and sometimes not having time to use the bathroom. The need for more time may have a psychological component. No one, including a parent, wants to be "on-call" and always in demand. They want to regain a sense of control over their lives -- to be responsible for their own mistakes and failures as well as to take pride in their successes. They want people around them who will listen and support. Ideally they would like to talk to someone who understands how traumatic brain injury is different from dealing with a long standing, congenital disability in your child. In this vein, they frequently report: grief for the "lost" child they knew and guilt associated with these feelings, difficulty learning to know a new and different child, and anxiety connected with "wondering if you are doing everything you can for your child and for your family." What parents do not need is criticism, overt or implied. Well intentioned suggestions, moralizing, or talking about personal troubles by the worker may add to parental distress, and, in general, would be avoided.

Traditionally, respite services are introduced as the answer to "creating time" for parents as if the only way parents spend extraordinary amounts of time is through childcare. In reality, however, having a child with a severe injury creates many other kinds of beyond-the-ordinary demands upon parents -- more record keeping and bookkeeping because of scheduling appointments, paying bills, filling out insurance forms,

submitting forms, checking reimbursements against submissions, troubleshooting errors in billing, learning new procedures for income tax, answering challenges from the IRS whose agents are amazed at the expenses, obtaining and submitting waivers to disclose information, securing reports, finding new specialists, etc.

Therefore, it makes sense that "creating time" for parents may best be done, in fact, by relieving them of other than caregiving kinds of burdens which not only sap time and energy, but which may be loathsome tasks for which the parent is ill prepared. Such tasks are often painful because they are constant reminders of how life has changed and of the additional day to day hassles required because of the injury.

What Specifically Frustrates Parents?

Experience: The first group of comments relate to the struggle parents have understanding the injury and getting services in an underdeveloped and fragmented system wherein even skilled case managers are often challenged.

- ***"Everything is a fight. -- The care-at-home program was a fight to get, and the amount of hours that we put in getting it started was amazing. We put in more hours -- and got nothing back, and we put more and more into it. We finally did get the care-at-home services, and thank God."***

- ***"Managing the paperwork -- all of the paperwork -- all of the contacts with the insurance companies and doctors and filling out forms and --"***

- ***"We have files, no lie, that must go right across this room on Brad's care and everything in duplicate. We made copies of everything."***

- ***"If you are not knowledgeable, there is no one who tells you."***

- ***"I had folders and folders of information, but I had to do it myself."***

A young mother commented on the hassles of appointments and the irony of spending extraordinary amounts of money to facilitate spending more money without being able to use one's own time and skills to offset the financial strain.

- ***"You are paying a babysitter, transportation -- You could end up spending 6 hours just going to the doctor's office -- meantime you pay the sitter $5 - $6 an hour to watch your kid and you're making nothing."***

Below two fathers comment on the physical demands of lifting and carrying their grown children. Implied may be the psychological hurt of being required to face their ultimate dependency by having to physically carry adult children. One father tells of having to put his daughter on and off the toilet (because of his greater physical strength) which means, of course, having to contend with her menses as well at certain times of the month. These fathers seem to be expressing hurt for themselves and for their children. Implied, yet explicit, is the fact that if they were not around to do these things, who would? (These are the kinds of services -- heavy lifting and intermittent in nature -- for which home health workers are not easily found.) The father in the second quotation, refers to the constancy of care, the always "on-call" nature of his job as he notes that his other daughter may have to call him out of the parent meeting in which these issues are being discussed in order to toilet his injured daughter.

•"He came home weekends (from the rehabilitation center) on visits to reacclimate him back into the community. Fine. That was great. (But) I had to transport my son, literally carry 100 lbs. into the car, out of the car, and down my mother's steps."

•"The care for Laurie. The fact that my other daughter says when she left here a while ago that 'I may have to come in and get you to put her on the toilet.' I wipe that girl. Help her with her monthly business. I do that. I am 66 years old, you know."

The constancy of care and the hurt that no one seems to want to help is expressed by the same father who, though technically retired, is more limited than most people who are working and leading typical lives.

•"Nobody comes to say, 'Hey, why don't you and Pat --" Nobody comes to give you a break."

Interpretation: Just as children are different and need different care plans, families and primary caregivers are different and respond differently to stressors. Everyone is better at some things than others; our society proceeds on that premise.

Some parents find that once they have experienced some success, they thrive on the case management and program issues involved in teaching and caring for their child. They take courses, go to workshops, read literature, do research and develop high level case management and system coordination skills. In some instances, governmental auspices have made efforts to train parents in such skills or at least to recognize and support those skills. In New York state the Office of Mental Retardation and Developmental Disabilities has given family support grants to parents for outreach, information, advocacy and referral services to other parents. In Minnesota, a Consumer Case Management Project (1989-1990)[3] paid small monthly stipends directly to families who acted as their own case managers and offered educational funds for those who chose to train for the role. Thus, some parents become "professional parents." Many of these parents engage in casefinding and act as advocates for others as well as themselves.

On the other hand, some parents have chosen highly technical work partly because they do not enjoy business interactions with people. These people may be terribly stressed by the need to make endless telephone calls, troubleshoot delays in equipment delivery for their children and deal with business offices which have made errors in accounts. The shopworker who struggles with learning disabilities himself and has always been stressed by paperwork will be enormously handicapped by having to write letters to officials, insurance companies, the school system, etc. In fact, even people who have been described as consummate bureaucrats, "knowing the system well," or being blessed with inside contacts, may find that what is required goes well beyond the responsibilities they have ever assumed before.

Thus, if we are serious about designing programs and services for families instead of "the client," then we need to individualize the kinds of assistance we make available instead of offering a one-size-fits-all childcare option. Such services will probably include professional level counseling from people who know the situation well, housekeeping help, record and bookkeeping services, and various levels of case management.

Many people believe that the growing isolation and finally alienation from the larger community is the ultimate stressor for children with TBI and their families. If this is true, we should be designing programs, services and supports to specifically prevent isolation and to promote integration and bonding to their communities. Assisting a family to entertain in their homes or to enjoy hassle-free outings with friends, establishing new contacts in the community, and sensitizing friends, neighbors and relatives to the kinds of help the family needs may be the most important service of all. And yet, I know of no agency which has that goal or acts as a facilitator of integration.

What is Wrong with Existing Services?

Experience:

•"No continuity of care -- I'm tired of training professionals. There's no continuity whatsoever."

•"The one that came into my home spent more time drinking coffee than working with Benjamin."
•"We have the care-at-home program. The woman comes in. First of all she can't bend over to put on my daughter's braces. -- The girl doesn't bathe her. My wife bathes her."

•"After about 3 months, my husband just left, he couldn't cope with it anymore, and now they won't even take her in a nursing home. -- They need qualified help badly. I mean, they send me people -- Medicaid will pay for aides to come in 24 hours. (But) they can't feed her. She is tube fed. They can't -- I'm lucky if they can change a Pamper. They just -- they send me young girls that are babysitters."

•"They don't believe that you know your child better than they do and that they are not listening to you, which is extremely stressful -- over and over -- telling the same story to everyone and no one listening."

Interpretation: Parents seem to be saying that they need and want workers with specific competencies who consistently respect their wishes. Most parents are probably more than willing to train workers if they know the worker will carry out the tasks as requested and if the same worker will continue with the family over a reasonable period of time. (The author once had the experience of paying a worker on 2 different occasions to come to the house to go through Jeff's care routine and get comfortable with the house. Before the date arrived when the worker was actually supposed to stay with Jeff, she had left the agency for a better job. Thus, she was paid 6 hours of wages for 6 hours of parent work with no respite in sight.)

It is emotionally draining as well as a waste of time and money to tell the same story over and over and to give the same instructions over and over. Further, parents have a right to expect a certain level of competency, initiative and industry from people who have committed to do a job. The very reason families are using the service is to save them from doing it themselves. In fact, sometimes they are left doing the hardest parts of the care or cleaning up after a worker. This negates the whole purpose of in home care and is one of the reasons that many parents express a desire for direct subsidies instead of vouchers so that they can hire, train and fire their own workers.

Section II: What Are Some New Directions for People Who Want to Help?

Section I represents a report and analysis of the qualitative research conducted, in part, under the federal grant from NIDRR, "Model Family-Professional Partnership Interventions for Children with Traumatic Head Injury." Section II represents possible new directions and is presented in the nature of a concept paper for the purpose of stimulating discussion, research and pilot programs. Individuals and agencies are invited to comment, and especially to share their programs and experiences.

The present condition of in-home support and in-home health related services appears to be of uneven quality and quantity throughout the state of New York and the country. While hundreds, perhaps thousands, of families are satisfied with the services they are provided, other parents have complained that the supports, services, and programs they need are non-existent or not easily accessed, expensive, fragmented, inflexible, unreliable, and often of low quality.

New Kinds of Supports and New Kinds of Services

A generic problem for parents of youngsters who have been injured, who are ill or who are recovering from surgery is that sometimes they need supports and not services. For example, at times parents prefer to take care of the child and the house themselves. They may feel the most qualified to care for, comfort and nurture their own children after a surgery, for example. They may feel deep satisfaction from the bonding their interaction with the child generates. In fact, they may feel distressed not to be able to care for their child and being required to have someone else, who is a virtual stranger and who will have no continuity with the child over time, know more about their child than they do! Yet if they cannot take leave from work, they may have no choice.

Some parents prefer not to have strangers in and out of their homes at all and are stressed by the decrease in family privacy this brings as well as the additional time required to orient the workers each day, etc. Thus, a support (versus a service) such as mandated family leave might be more appropriate for many families. Another example of support versus the traditional service would be public transportation which is wheelchair accessible and the donation of a ticket to a hockey game versus the "companion sitter" for an 18 year old who has suffered a TBI. With the former support, the young man could get out for a normalized activity, perhaps with a friend, and the parents could choose a quiet evening at home, enjoying their leisure and their privacy, instead of feeling "forced out" which so often happens when a worker comes in. The challenge for society is to identify what is most helpful to families, not necessarily to increase services.

Expanding Supports: An additional problem of families with children who have sustained traumatic brain injury is that many of the kinds of services they report needing are not available to them at all. For example, counseling is often not reimbursed by insurance or is reimbursed at low levels which require substantial deductibles and copayments. Likewise, other services such as comprehensive case management, advocacy, specialized information and referral are not funded, and, therefore, unavailable to many families. The Report of the Surgeon General's Workshop on Children with Handicaps and Their Families, (Public Health Service, 1985)[4] underscored this problem, stating, "Health care service providers are finding an increased demand for their services and products, but mechanisms for reimbursement do not meet the diversity of services they can provide and the cash flow they require for operation. They seek guidelines for meeting a standard of care and mechanisms of coordination and communication with health care facilities, third party payment agencies and insurance companies."

Some supports and services are not covered because they are not "medical" or "health-related." Psychosocial services to the child or family may fall into this category. Because these services are not widely funded, they also tend to be underdeveloped. Few would argue that children with cerebral palsy, spasticity and communication problems need to be treated by specialists. These services and therapies have qualified for insurance and Medicaid coverage. Few would argue that children with spina bifida, paralysis, neurogenic bladder and scoliosis need equipment and therapies. Braces and surgery are routinely prescribed, urinary tract infections are treated and other therapies are provided and reimbursed. For many children with TBI, it is to be expected that the injury to the brain will result in memory loss, disinhibition, confusion, emotional lability, and atypical behaviors. Cognitive and behavioral therapies, social skills training, and psychological interventions are the comparable "medical" and health related services for the TBI population. Not to fund these services would seem to be discrimination on the basis of a handicap and therefore against federal statute. Yet these services are often not recognized as qualifying for insurance and Medicaid coverage.

Further, the requirement that only traditional treatments and therapies qualify for private pay insurance or publicly funded coverage, limits the kinds of professionals available for service delivery to nurses, therapists, health aides, etc. when other specialists (neuropsychologists, cognitive therapists, behaviorists, educators, therapeutic recreation workers, etc.) may be more appropriate.

Some services which would be helpful or even critical to decrease family stress and promote health and welfare are currently not even identified as services, let alone reimbursable services. These include record keeping, making appointments, arranging or providing transportation, investigating laws, preparing for fair hearing procedures, evaluating various facilities and programs. These kinds of tasks often go beyond the scope of a professional case manager. And most families do not have case managers at any rate.

A major challenge, then, is to educate administrators, legislators and providers that these "expanded" services and supports are as sensible and necessary as childcare and "respite" and must be funded directly. An "in-kind" relief could be offered to families who perform the direct care service themselves at the sacrifice of normal living. For example, when no one can be found to take care of the child -- lifting, toileting and bathing, doing range of motion exercises and cognitive exercises -- which may take the parents several hours each day, some mechanism should be set in place to have someone else tend the garden or help with housework and laundry to compensate the parents and normalize their lives.

Policy makers have consistently resisted funding the kinds of services which look as if they are providing non-essential services, equipment or supplies, that is, those which are not clearly and wholly related to the individual child's care. For example, a low income family in an apartment may be able to get by using a laundromat for their family's typical needs. Cloth diapers for an incontinent child, however, cause embarrassment and frustration in using public machines as well as a problem finding someone to care for the child while the parent goes out to do laundry. For a suburban or village family, the only way they may be able to take a child in a wheelchair with the family - or even to extensive outpatient appointments might be to purchase a van and lift. Although the cost would likely be less than the costs of admission planning and 3 months of residency in an out-of-home placement, public funds will not pay for such a purchase. For a family with a child who has severe behavior problems which result in destruction of furniture and walls, the most supportive use of funds may be for periodic redecorating. But how many agencies would be willing to fund that? Likewise, the constant banging of a wheelchair takes a heavy toll on woodwork and the excessive dirt from the wheels will soil and even ruin carpets far more quickly than usual. Public funds will, of course, pay for home repair, maintenance and reasonable household replacement items in community residences ("group homes"), nursing homes, and institutional settings run by provider agencies, but not for families.

In New York State, the Commissioner of the Office of Mental Retardation and Developmental Disabilities has targeted the development of family-centered supports as a major agency direction. A Bureau of Consumer and Family Supports oversees the family reimbursement program which began in 1989 and has grown to 15 operating programs in 1991. The Commissioner has also instituted special consumer and family advisory bodies and assigned a special assistant for innovations to deal with family issues. The special assistant is charged with doing "whatever it takes" through personalizing services, securing equipment and supplies, etc. by coordinating with other agencies and developing multi-agency packages of support. Further, Governor Mario Cuomo has announced that a Board of Innovations has been created in the Governor's Office to stimulate new approaches and authorize necessary changes at the highest levels for successful implementation. It is expected that, together with the Home and Community Based Services Medicaid Waiver Program, more equitable resource distribution will be possible for families. Bringing what are now considered ancillary services into general acceptance may require criteria which clearly acknowledge and associate the service with the additional responsibilities arising from the child's injury, but it appears that direct subsidies or reimbursements to families also need to be part of a comprehensive approach. Families should be trusted to choose which kinds of relief they prefer to balance out the extraordinary psychological stress, the additional expense and the atypical time demands caused by the injury and to be expected to do that at least as wisely as any other provider.

Another kind of reform which has potential to provide choice to families in communities is New York's Neighborhood Based Initiative (NBI) which is administered through the Department of Social Services. This re-forming effort at state and regional levels seeks to promote broad community involvement in designing the services which "fit" given communities. It is hoped that services and supports will be personalized to target populations and to their immediate environs. Local Community Advisory Councils design the programs and apply for grants. A state oversight committee is charged with identifying existing funding streams to implement the program. Further, the oversight committee may waive regulatory requirements and request changes in law as well. Other powers are the capacity to issue unified contracts which blend governmental, other public and private funds, the capacity to use special "service gap" funds, and the authorization to transfer funds from other sources to DSS under limited circumstances. Because of the Americans with Disabilities Act which prevents discrimination and mandates access and inclusion and because of a renewed interest in family supports, the NBI may serve as a pilot for providing flexible and normalized supports for families of children with TBI at the local level.

Related Medicaid Reform: On federal level, Senator Chafee and Senator Waxman have promulgated reform legislation which would address some of the issues discussed in this paper over the past few years. Political and economic resistance has effectively scuttled the proposals. However, a precedent has been set with the new state plan option for Community Supported Living Arrangements (CSLA), section 1930 of Title XIX, which was amended by the Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508). This step toward Medicaid reform provides for federal funding for services that are non-medical in nature, including training and rehabilitation, personal assistance, assistive technology and adaptive equipment, support services, and emergency assistance.
Another significant feature of the legislation is that there are no requirements for being in an institution at application, having been in an institutional type setting or being at risk for institutional care. In fact, eligible persons must reside in their own home/apartment or with no more than three other persons. Two to eight states will receive the authorized $100 million over 5 years. While this reform is an important conceptual step, it is inadequate for true "equal protection under the law" for families who have cared for their children at home at great sacrifice.

Expanding the Scope of Worker Expertise and Practice: How does one bridge the gap between the hospital, the rehabilitation center, the home and the school? How does one assure that direct care workers will know how to increase learning in the child, build self-esteem in the child, and help the child with homework or therapies? How does one increase appropriate behaviors in the child instead of reinforcing isolation, acting out or other undesired behaviors? How can the social isolation of the child and the family be reduced?

The Professional Consensus Conference convened by NYSHIA in 1990 recommended a new kind of professional who might combine some of the qualifications of a clinical case manager with the role of an integration facilitator. This paper expands that recommendation to include hands-on interaction with the child and the family and thus integrates skilled care, case management, and integration. A recent publication (1990)[5] reporting on the work of the Human Services Research and Development Center in Minnesota addressed the integration of these functions by pointing out that human service workers have become sophisticated about identifying deficits in all kinds of skills, but have not paid any significant attention to the human relationships that make life worthwhile.

"We are helping people be more competent, but they are still alone."

"It is possible that a significant, if not primary role, for staff can be that of community connector. Staff can be people whose job it is to introduce people with disabilities to others, and who support their relationships with people who are not part of the service system. That is a vastly different role than teaching people what they don't know, or providing for basic needs of shelter, food, and daily needs, all of which are important and not to be ignored. It is also a very different role than 'training social skills.'

Being cared about by others who really like you is one of the basic needs of human beings. So is having a sense of self-esteem through knowing that you're valued and cared about by others who are also valued. Staff can take care of the meeting of these needs as one of the most important parts of their jobs."

Some of the attributes of this new role have been encompassed in the liaison/facilitator role discussed below. The liaison/facilitator would work directly with: 1.) the child to increase personal competencies and community connections, 2.) the family to understand their values, needs and strengths, and 3.) the direct care worker in the home. (The word "aide" is de-emphasized in this paper to reflect the fact that the direct care worker, if needed beyond the liaison/facilitator, will have a different role, different capabilities/responsibilities and different status from an aide. Therefore, the person is simply referred to as the direct care worker.)

The Goal and the Role: The "new" kinds of professionals and paraprofessionals would have responsibility to both increase the child's level of function and deliver family centered service. The goals of the liaison/facilitator would be:

- to increase personal growth and competencies in the child
- to serve the family's interests as they express those interests
- to provide coordination between service providers in the home, the school and the community, and
- to use generic, typical and valued resources in the neighborhood and community to create acceptance and support for the child and the family.

Agencies could begin to hire professional liaison personnel who are qualified to work with hospitals, schools, families and the larger community. These professionals would have a new role which includes: 1.) actual "hands-on" practice themselves, and 2.) training of direct care workers largely through modeling and participatory planning. This role is distinctly different from the role of the professional as a nurse supervisor, case manager, or therapist.

This new kind of professional would be closely matched to the needs of the child and family. That is, if the child's primary problem is behavioral, the liaison/facilitator must have related training and background (clinical psychology, behavioral studies, etc.) If the child is on a ventilator, the professional liaison/facilitator may be a nurse with developmental expertise. Occupational therapists, psychologists, and other human service workers with developmental and/or rehabilitation backgrounds are good potential candidates for these positions as are parents of children with TBI who have some specialty training and experience or are willing to study directly related skills.

The liaison/facilitator is not simply a "professional consultant" or "therapist." This new role demands broader duties in the direct care of the child on at least a weekly basis so that the liaison/facilitator knows first hand what works and what doesn't. It is suggested that the liaison/facilitator spend at least 5 hours a week with the child and in the family home. He or she must know what needs to be adapted or changed and should have a feel for how long given tasks take.

The liaison/facilitator fills some case management functions but has a broader role. Case management functions become an integral part of the caregiving. The liaison/facilitator makes telephone calls to arrange transportation, finds appropriate educational software for the child's computer, or schedules physician appointments, from the family's home in between other direct interactions with the child. The appointment times are put on the calendar and the catalogue is dog eared so that the parent may know immediately what is happening and comment accordingly.

Examples:

•The child who is medically involved and receives out-patient therapies will have a liaison/facilitator with a nursing or similar background to accompany him to significant appointments. This professional will

interpret and communicate therapy goals and care techniques to the family and to the direct care worker. He or she will also interpret the family's values and goals to the physician or therapist, explain the limits of resources, describe what seems to work, give impressions of the way the treatments or therapies affect the child on a day to day basis, and call attention to developing needs or strengths of the child and/or family which may be utilized.

•The child who is primarily in need of recreational or social interactions will have a liaison/facilitator with a background in therapeutic recreation or a related training. This person would not only spend time playing games with the child, but would carefully observe the child at school, would investigate what kinds of games and sports are the usual fare for his peers, would talk with the physical education teacher about adaptive techniques, but would also act as a community connector.

The professional might invite schoolmates, neighborhood children and others to interact with the child after school or in a small group at a local park and teach them new skills at appropriate intervals. This liaison/facilitator would seek out and arrange for trips to community activities such as movies, plays, baseball games, the library, craft shows, museum exhibits, and would do the preparatory and follow-up work which increases learning and skill as well assures recreational value.

Teaching/Training Functions: To deliver this service in a cost effective way requires that in addition to the liaison and coordination role, the professional uses clinical and programmatic skills in a teaching/training function for the child, family members, and the paraprofessionals who also work directly with the child. The liaison/facilitator always schedules some interactions with the child and family during times when the other direct care worker(s) are on duty so that he/she can model techniques for the worker, oversee what the worker is doing and bring any problems the family has to the worker's attention in a skilled and professional way.

The liaison/facilitator assists in increasing both the scope of responsibility of the direct care worker and the skills required to carry out the additional responsibilities. For example, in participatory planning the direct care worker may have some ideas for adaptive equipment; the liaison/facilitator brings an adaptive equipment catalog and requests that the worker search it. If something looks beneficial, it is discussed with the family and possibly pursued through an appropriate professional or ordered directly.

The liaison/facilitator uses some of the same techniques she/he uses with the child (modeling of behavior, immediate feedback, coaching and support) to teach the worker to make selected calls, to do selected filing or record keeping related to the child's care and to take other responsibility in an accountable way. Such an approach should increase the quality of the child's care as well as increase the family's satisfaction with service.

Benefits for Families: Anticipated benefits to the child and family are many. The child receives the benefit of a professional with specialized competencies matched to his or her needs at any interval of time. This alone meets one of the most frequent concerns expressed by parents. Further, there is one point of responsibility. The professional is likely to develop empathy as well as good management insight because he or she closely approximates the family in the scope of responsibilities and the manner, time and place they are carried out. This is very different from the situation where an agency nurse supervisor, parent trainer, or therapist comes into the home for a 30 minute session for a specific purpose.

Communication is improved since there is almost immediate feedback on the days the liaison/facilitator works in the home. There is ongoing communication between the liaison/facilitator and the direct care worker as well. The liaison/facilitator encourages good communication between the family and the worker, but can act as a "buffer" between the family and the direct care worker when necessary. Increased job satisfaction for both the professional and the paraprofessional is expected to result in less turn-over and greater continuity and bonding for and with the family.

Benefits to the Workers: Many professionals have complained about the lack of balance in their jobs: "I've become a clipboard nurse; I miss the hands on care." Direct care workers often complain about their

supervisors. "They don't know what it's like. She's paid twice what I am. I do all the scut work, she goes to all the workshops on client care," or, "I haven't seen a supervisor on the job since I began."

The professional's job should be more balanced and the direct care worker's job should become more interesting. Both workers will be developing marketable skills, and elevating personal status and the status of family centered service. Better status, job opportunity and worker satisfaction should result in less turnover and more satisfaction. Recruitment should be easier for agencies and families should experience better access to high quality care.

Benefits to Society: The use of liaison/facilitator professionals is cost-effective because professional time is used in new ways. The liaison/facilitator has a small number of families, probably 4-6 whom she knows intimately. Direct care workers become more efficient with the ongoing, active training and interactions they receive. Because interventions are timely and programmatically sound, one would anticipate that problems experienced by children are prevented before they become extreme and require expensive, specialized interventions. Many ongoing specialized services may be replaced by supports and services which are commonly available to all of the citizenry. (Children may begin to use swim programs conducted by the local park or "Y" and story hours at the local library after planned and supervised efforts to integrate them.)

Assessments upon which plans and major resources are based should be more accurate, thus avoiding costly mistakes, both for the child and at the family level. A plan which incorporates the entire family means that each member of the family is valued; inexpensive interventions which are timely can be utilized in order to prevent problems from exacerbating. If the precursors to problems such as alcohol or substance abuse, abandonment of the family, and depression can be identified and addressed, interventions will be far less expensive than treating the results. The professional knows quickly what is needed, what has changed and what works and what doesn't. This avoids costly trial and error and conserves resources.

Professional accountability is based upon the need to share information and expertise with direct care workers in a routinized and on-going way. Modeling, immediate and intermittent reinforcement are some of the most powerful teaching tools known to humans. The increased status and skill of direct care workers should be a positive societal force for motivation in caring for the vulnerable among us in society. The family orientation of all services reinforces a long standing societal value of supporting the family and seeks to transform that value into practice.

The use of generic supports and services benefits all of society by developing what is useful for all citizens. This should also decrease the "blame the victim" attitudes evident especially in times of extreme fiscal troubles. The major role for coordination of services strengthens the positive aspects of the American privatization philosophy (choice, competitive prices, innovation, etc.) while compensating for the weaknesses inherent in the system, namely, fragmentation, duplication, and competition for resources.
Independent Contractors: This new role of the liaison/facilitator may be filled through independent contracting with various professionals in the community or through an agency. As waivers for services become more available, it is expected that families will select, hire and train their own workers, for various kinds of roles, more frequently.

Parents as Case Managers: Some parents or family members desire to be their own case managers. Training, stipends and status should be available for those who are willing and qualified to case manage. A project in Minnesota made funds available to parents so that they could be trained to do the job competently; their time and talent was recognized with payments.

"Although the cash and educational money given to families was not seen as the most important aspect of this project, a majority of participants indicated that receiving money for the extraordinary effort involved with coordinating services was rewarding. More importantly, parent case managers, in particular, indicated that the knowledge that they had access to training funds to use at their discretion and knowing

that they were being paid, however, minimally, was empowering. They felt on a more equal footing with the professionals in their lives. The total amount of money allocated to each participant was only $630.00 annually. **Paying parents for providing case management services and paying for adequate training may serve as a cost effective way to improve the quality of case management services in Minnesota."**[6]

Considerations for Agencies

The liaison/facilitator is a new concept for the family support field. It may be that some home health agencies would be in a position to try it on a pilot basis. The following section deals primarily with ideas for existing agencies to consider as possibilities for improving services.

A Sense of Mission: Every agency should have a mission statement of 10-15 words which every employee knows by heart. It might reflect the view that support and a mindset of serving is preferable to service. It might encompass the belief that all people in trouble deserve a nanny or a valet to ease their way. In some way, the statement should reflect that the agency caters to and respects the child and family whether or not they are the direct payor.

Getting There: Most agencies have tried various ways to address the "no show" staff problem often by incentives which do not recognize that some workers are so financially strapped that they simply do not have reliable transportation or reliable childcare themselves and often are so stressed in their personal lives that they have more emergencies than people with greater resources and greater coping skills. While incentives should always be part of the strategy, other systems approaches should be explored.

One mechanism might be to create a pool of direct care workers who are placed upon retainer. The retainer technique is designed to assure that people who are critically important to a business or agency's performance will be available if and when they are needed; the assumption is that it is worth guaranteeing these people a certain amount of money to assure that they will "drop everything" in order to give priority to important and sometimes immediate need. Although retainers are usually reserved for attorneys and high power, highly specialized professionals, the device could be used for the "little guy" who is the backbone of home care.

Agencies might subcontract with individuals or join an interagency pool which all agencies in a region share. Every agency might pay on a quarterly basis for x units of service, with holiday and night hours weighted higher than others. Or, the agency might place all staff, including every manager and supervisor, on rotating "on call" duty, so that everyone periodically does hands-on service.

Further, it might be that just as some organizations grant mental health days to their workers, the agency which specializes in home care could let each worker know that they expect that there will be a certain number of these "no show" days. Instead of penalizing workers for bona fide emergencies beyond their control, the agency might use their emergency, on-call or substitute system to support workers and reinforce the meaning of the agency's mission by making everyone at every level responsible for excellent coverage even in the face of emergency. Individual incentives could be part of such a systems approach. Workers could be allowed to "buy back" their allotted number of days (for pay, for vacation time or for tuition credit, etc.) if they did not need to use them.

An agency could also contract, perhaps on an interagency basis, with a vehicle rental service so that they could make a commitment to get children to physician appointments using wheelchair accessible vans

which neither the agency nor the parents alone can afford, obtain a loaner vehicle for a valued worker in an emergency, or even provide specialized and adapted recreational vehicles to families so that they may vacation with their child who uses a wheelchair.

Knowing How: Agencies should learn to work with those who have an abiding commitment to families and to children with special kinds of problems. They should seek to hire parents who are otherwise qualified and to view their experience in a positive light. When parents, family members, or association volunteers are asked to do in-service presentations, they should be reimbursed for the sitter they needed, the gas they used, and the parking fee they paid. These people should be valued for they often have a breadth and depth of knowledge approached by few professionals which they are often more than happy to share.

Likewise, the advocacy organizations which represent traumatically brain injured people and their families need to be sought out for their experience and expertise. Often these agencies have conducted some kinds of formal research or analysis of their constituents' needs. Even when that has not been possible, such organizations may be pleased to give you impressions which are likely to be accurate. Additionally, they may be willing to work on creating a protocol for formalized research or archival analysis or to participate as a subcontractor for various grant projects.

Working Together: In New York State, the New York State Head Injury Association is the official chapter of the National Head Injury Foundation. At the grassroots level, NYSHIA has 30 chapters and support groups. The Association has received grants from many major State agencies, such as the Department of Health and the Office of Mental Retardation and Developmental Disabilities as well as working with major universities. NYSHIA has experience in providing professional education to various groups and has placed a high priority upon the stimulation of family supports and family centered home care. The Association is blessed with a large membership which includes many parents, survivors of TBI, professionals and provider agencies, many of whom are available for consultancy. For further information, please write or call our office: 855 Central Avenue, Albany, New York, 12206, Telephone: (518) 459-7911.

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References

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Appendix

Important Unmet Needs of Families as Reported in NYSHIA Family Questionnaire Survey Research. 1990

We asked families to rate on a scale of 1 - 4 how important 39 different needs were; respondents could also choose not applicable. Respondents were also encouraged to add other needs on lines marked a, b, and c and were provided with additional space for written answers. The directions noted that needs change over time and asked respondents to answer how important the needs are *at the present time*.

The most frequently chosen needs ranked by "very important" status were:

- to have my questions answered honestly
- to have complete information on my child's problems in thinking (for example, confusion, memory, or communication)
- to have complete information on my child's physical problems (for example, weaknesses, headaches, dizziness, problems with vision or walking)
- to have explanations from professionals given in terms I can understand
- to have enough resources for my child (for example, rehabilitation programs, physical therapy,counseling)
- to have a professional to turn to for advice or services when my child needs help
- to have information on my child's therapy or educational progress
- to be assured that the best possible medical care is being given to my child
- to be shown that medical, educational, or therapy staff respect my child's needs or wishes
- to be told about all changes in my child's medical status
- to have complete information on the medical care of my child's disorder (for example, medication)

Additional information about unmet need was assessed through another question regarding services. In asking primary caregivers about the services that were actually used or available to the child or family, we listed 22 kinds of services, including inpatient services, foster home, group home, skilled nursing facility, and special education. It should be noted that in the field of developmental disability, and probably more broadly in human services, some of these services would not be considered as "support services."

Support services usually imply that the child is "at home" and primarily cared for by the family. Mechanisms (such as employee family leave policy) and services which are not entitlements (respite services for the caregivers) are generally considered ancillary or "supporting" in nature. Likewise special education which is mandated for children with certain levels of disabilities would be considered an essential service, not a support service, as would physician visits and inpatient hospital stays.

About the Answers: A chart was prepared and directions were provided to aid respondents in selecting 1 of 5 categories on the grid: 1.) actually used, 2.) would have used if we had known about it, 3.) would have used if we had the resources, 4.) wanted but was turned down, and 5.) did not need.

Large numbers of respondents did not answer various items at all. For example, approximately 220 people failed to answer regarding group home, skilled nursing facility, and intermediate nursing care facility. Two hundred and twenty six (226) people failed to respond to the "foster home" category. It may be, for example, in the case of "intermediate nursing care facility" caregivers did not understand what was meant unless they had direct experience with this level of care. These parents may see choices such as nursing homes and foster homes as extreme options, not typical or appropriate for their children. In any event, although suspect numbers failed to respond to the category at all, fifty seven (57) people reported actually using out-of-home facility services (skilled nursing and intermediate care facilities) and another 23 reported that they would have used these facility based services if they had the resources.

The highest demand in the "would-have-used-if-we-had-known-about" category, is for support group, free health maintenance organization, financial counseling, sibling counseling, and family counseling in that order. Other unmet needs, which clustered at approximately 25 people each, were: housekeeping services, out patient psychiatric services, marriage counseling, in-home and out-of-home respite, vocational rehabilitation and transportation services.

In rank order, the highest unmet needs under "would have used if we had the resources" were: financial counseling, free HMO, and sibling counseling, followed closely by in-home respite, housekeeping services, and individual, marriage counseling and transportation.

Both the parent consensus group and the survey respondents expressed a need for support services: counseling for the individuals in the family, including marriage partners and siblings, and a need for respite and hands-on help in the home. Both groups indicated that they had important needs which go beyond the traditional medical and health categories typically covered by Medicaid or insurance.